



Facing End of Life

A guide for people dying with cancer,
their families and friends

Practical
and support
information

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13 11 20



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Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.



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Introduction

This booklet has been prepared to help you understand more about the issues facing people who are dying with cancer. We hope it will provide support and direction during this period.

If you have had cancer diagnosed at a late stage, or if the treatments have stopped working and remission or cure is no longer possible, you may be told that the cancer is end stage or terminal. Everyone copes in their own way with this news. Your reaction may depend on your age, family situation, cultural background and spiritual beliefs.

The chapters in this booklet outline the emotional impact of knowing you are dying, what might happen physically, and how you can prepare for death. There is also information for carers, family and friends. This may be the first time you have read about end-of-life issues. Take your time and check the introduction to each chapter to see if it is information you want at this stage. Read what seems useful now and leave the rest until you're ready.

Cancer Council also produces the booklets *Living with Advanced Cancer* and *Understanding Palliative Care*. You may find that one of these is more relevant to you at this time.

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.



**Cancer
Council
13 11 20**

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Coping with the news that you're dying

This chapter discusses the different ways you may cope with the news that you're approaching the end of life, and how your family and friends may cope. Everyone reacts in their own way. It is natural to feel a range of strong emotions and for these feelings to change often.

Hearing the news

Learning that you may not have long to live is shocking news. Even if you are aware that the cancer is progressing, hearing that you are dying can be devastating.

We all know that death is a natural part of life and that it will happen to us all one day, but most of us hope that we won't die anytime soon. Realising that death is close can be frightening and hard to believe. For some people, however, it may be a relief. You may have questions straightaway, or you might need time to absorb the news and come to terms with the prognosis.

Your feelings

After the initial shock, feelings of fear, denial, anger, despair, helplessness and anxiety are common. You may also worry about being a burden to family and friends – emotionally, physically, socially and financially.

You probably will have more than one emotion at a time. These feelings are likely to change, sometimes from day to day or even from hour to hour. This is often part of the process of making sense of what is happening. You may find it hard to think clearly. It's natural to cry, so don't feel like you have to put on a brave face.

Many people compare these feelings to waves at the beach. The first waves may knock you off your feet, then your footing becomes a little stronger. But, at any time, a large wave can suddenly come back and knock you off your feet again.

“ I’ll be sitting there watching telly and suddenly remember that I’m dying...It’s a suffocating feeling, all jumbled thoughts – it’s 60 years of memories at once. I’ve found a cure though: I just get in the bath. That’s the only thing that relaxes me now. ”

Victor Fournere, ‘Living with death’, The Observer, Sunday 19 June 2011

The waves of emotions may not hit in any particular order, but people often say that their fears are stronger when they’re lying in bed at night, and that they rarely share them with others.

These feelings probably won’t go away altogether, but they may change over time. You may work out strategies that help you cope. Find someone you can talk to, perhaps a family member or friend. You could also consider seeking professional help through a palliative care specialist, general practitioner (GP), counsellor, psychologist, psychiatrist or spiritual adviser. Other people who are nearing the end of life offer a unique perspective, so you may want to consider joining a support group (see page 77 for details).

Telling others

People share the news in different ways. There is no easy way to start this conversation, but you may find it helps to prepare.

- When you feel ready, decide who to tell and what you want to say. Think of answers to possible questions, but only respond if you feel comfortable. You don’t have to share every detail.

- Choose a quiet time and place.
- Accept that people may react in a number of ways. They may be uncomfortable and perhaps not know what to say. If they get upset, you may find yourself comforting them, even though you are the one dying. Another common reaction is denial – they may be convinced that the doctors are wrong. Some people may find it difficult to be around you, and you may feel abandoned by people you thought would be supportive.
- Call Cancer Council 13 11 20 if you need help telling people. They can help you find the words that feel right for you. Another option is to ask your doctor or nurse to help you share the news.

For ways to talk to people (including children) about dying, see the *Emotional and spiritual concerns* chapter on pages 19–26.

Do people who are dying need to be told?

Sometimes family members learn the cancer is terminal before the person who is dying. They may think the person is too young or too old to be told the truth. Some cultures may also think it's best that the person is not told.

Usually people who are dying know what is happening.

Keeping it a secret from them may mean they feel isolated at a time when they most need support. Ask the person if they would want to know and follow their wishes. The health care team can help you with this conversation and also with an approach for complex situations, such as when the person dying has dementia.



Common questions about dying

Knowing that you're approaching the end of life raises many questions. Sometimes, you may not be sure if you want to know the answers. This chapter discusses some of the questions you may want to ask when you're ready.

How long have I got?

Some people want to know how long they have left to live, while others prefer not to know. It's a very personal decision. This question can be hard for your doctor to answer and you may find their response is vague. As everyone is different, a doctor can give you an estimate (prognosis) based on what usually happens to people in your situation, but can't say exactly what will happen to you.

Some doctors may sound very definite about the amount of time left to live, but it is only ever an estimate. Other doctors may be hesitant in case they overestimate or underestimate the time. But you can ask for an estimate if it is important to you. They will probably talk about your remaining life span in terms of days, days to weeks, weeks to months, or perhaps even longer.

You may want to think about whether quality of life or the amount of time left to live is more important to you. Some people might choose to have less time if it means feeling relatively well, while others want as much time as possible, regardless of how they feel. Sometimes people find that near the end they change their minds and want to do everything possible to postpone death, if only by days. This is a natural reaction. Talk to your family and your health care team about your preferences, and let them know if these preferences change.

It is likely to be very difficult if you are told that the time you have left to live will probably be short. Even if it is only a matter of weeks, having a sense of how much time might be left can give you an opportunity to prioritise what you'd like to do.

If you live past the estimated time, you may feel unsettled and not quite know what you should do next. Or you might feel lucky to be living beyond that time. It may help to talk about your feelings with your family, the palliative care team, your doctor or a counsellor.

“My doctors haven’t ‘given me a date’ but I’m preparing for the day. I’m getting my affairs in order and trying to make sense of things.” Agnes

Is now the time to try complementary or alternative therapies?

If your doctor has told you that the cancer cannot be cured, you may wonder whether there are other therapies you could try. Complementary therapies are used alongside conventional medical treatments, while alternative therapies are chosen by some people instead of conventional treatments.

Many people use complementary therapies to help them feel better and cope with cancer and its treatment. This is also true for people who are dying with cancer. Complementary therapies may help you relax and reduce anxiety. They can also be useful in managing symptoms such as pain and nausea. Some people find gentle therapies, such as massage and aromatherapy, helpful. People who find it uncomfortable or painful to be touched may prefer meditation or visualisation. Cancer Council produces a free booklet about complementary therapies – call 13 11 20 for a copy or visit your local Cancer Council website.

Alternative therapies are often promoted as cancer cures, and family members, friends or even strangers may suggest you try them when you explain your prognosis. Unlike conventional medical treatments, alternative therapies are not scientifically tested or proven to be effective and could be harmful. They can be very expensive and could affect management of your symptoms. If you have questions about a particular alternative therapy, talk to your doctor, call Cancer Council 13 11 20, or visit iheard.com.au.

It is important to tell your doctor if you are using, or considering using, complementary or alternative therapies. Some herbal preparations, for example, can interfere with other medicines.

What is the role of palliative care?

Palliative care helps people with cancer to live as fully and as comfortably as possible. It can identify and help you manage physical symptoms, such as pain, but it can also help with practical, emotional, spiritual and social concerns. It can help you live as well as possible right until the end of your life.

Because it is a family-centred model of care, family and carers can also receive practical and emotional support.

A team of health professionals, as well as volunteers and carers, work together to offer a range of palliative care services. The services will be tailored to your individual needs, but may include:

- relief of pain and other symptoms (e.g. nausea, vomiting, shortness of breath)
- resources such as equipment to aid care at home

- assistance for families to come together to talk about sensitive or complex issues
- links to other services such as home help and financial support
- support for emotional, social and spiritual concerns
- counselling and grief support
- support for people to meet cultural obligations
- referrals to respite care services.

Although it is not just about end-of-life care, palliative care plays an important role in offering symptom relief, support and comfort to people who are dying. The team will also support your family and carers to help them cope during the illness, and after the death.

Your palliative care may be coordinated by your GP, a palliative care nurse or the specialist palliative care team in your area. Specialist palliative care teams see people with the most complex needs, but they can also advise other health care professionals on ways to control symptoms.

Palliative care can be provided in the home, in a hospital, in a palliative care unit or hospice, or in a residential aged care facility. Services vary, however, because each state and territory has its own approach to delivering palliative care.

For more information about what palliative care is, how it helps and how to access it, call Cancer Council 13 11 20 for a free copy of *Understanding Palliative Care* or download it from your local Cancer Council website. You can also speak to your health care team or contact palliative care organisations (see page 77).

Who does what?

Wherever you receive end-of-life care, the different health professionals in your palliative care team can be called on as the need arises. They will work together to help meet your physical, practical, emotional and spiritual needs, and provide support to

The palliative care team

GP	continues to see you for day-to-day health care issues and may coordinate your palliative care
specialist palliative care nurse	may work in a community or hospital setting, can provide ongoing care and may coordinate your palliative care
nurse practitioner	has had additional training and may be able to prescribe some medicines and referrals
palliative care specialist or physician	prescribes or recommends treatment for more complex symptoms associated with advanced cancer; usually works in collaboration with your GP or palliative care nurse
cancer specialists (oncologists and surgeons)	may refer you to the specialist palliative care team and continue to provide cancer treatment to help manage your symptoms
pharmacist	gives you access to prescription and over-the-counter medicines to take at home; provides advice on safety and side effects; helps you keep track of your medicines
occupational therapist	can suggest aids to help you maintain mobility, and may assess your home and suggest equipment, such as hospital beds, wheelchairs and bedside commodes
physiotherapist	helps you manage daily activities; can use physical methods to help with pain relief and lung congestion

your family and carers. You may not need to see all of the people listed below, but understanding the different roles can help you work out what support is available and who to ask about particular issues. Your care may be coordinated by your GP, a community or hospital palliative care nurse, or the specialist palliative care team.

diversional therapist	offers recreational activities to improve your wellbeing
dietitian	works out the best eating plan for you and tries to use diet to assist with digestive issues, such as nausea or constipation
speech pathologist	may work with the dietitian to help you manage eating and swallowing problems
social worker	offers counselling and emotional support; provides information and referrals for legal and financial matters, help at home, and other services; and can help you record your memories
welfare officer	can provide information and referrals for legal and financial matters
counsellor, psychologist or psychiatrist	helps you work through grief, fear and other emotions; can teach you meditation or relaxation exercises; a psychiatrist may prescribe medicines to help with managing your emotions
spiritual care practitioner (pastoral carer)	talks about any spiritual matters and helps you reflect on your life and search for meaning, if appropriate; may arrange prayer services and other religious rituals
volunteers	can help with home or personal care and transport, and also offer companionship

What is a ‘good death’?

People often talk about wanting to have a ‘good death’. What dying well means is unique for each person, shaped by individual attitudes, cultural background, spirituality and medical treatments.

Think about what dying well means to you. Many people have found that it helps to:

- know that death is coming and have some understanding of what to expect
- have some control over pain relief and other symptoms
- be able to retain some control over where death occurs and how it happens
- maintain a sense of dignity
- have the opportunity to prepare for death
- reconcile damaged or broken relationships
- have the chance to say goodbye
- resolve regrets
- be able to have a say in end-of-life care and ensure wishes are respected.

There is more than one way to die well. Some people see staying at home (see pages 36–37) as the key to dying well, but others feel more supported spending their last days in a hospital or palliative care unit. The important thing is that your family, friends and health care team understand what matters most to you. Open conversations and planning ahead for dying and death can also help family members and friends cope better with bereavement. They may feel a sense of peace knowing that they helped you to die according to your wishes.

What is it going to be like?

It's common to have misconceptions or fears about what dying is like. Many people say they don't fear death as much as the unknowns of dying. Having some idea of what to expect can make the process easier, while not being prepared for what might happen can be distressing for you as well as for your family and friends.

If you've been with a person who has died, this experience will influence how you feel about dying. It may have left you reassured, thoughtful, sad, angry or scared. You may have been disturbed by some of the physical changes that happened to the person. For example, perhaps it appeared they were having trouble breathing, or they seemed to be in pain or uncomfortable.

It will help to talk to your doctor or to the palliative care staff. They can explain the physical dying process and reassure you that you will be cared for.

Modern health care means that people should not die in pain or distress. If you have symptoms that are not well controlled, you can ask a palliative care team to help. The information on the next page also describes the physical dying process in more detail.

“When patients ask me about the dying process, I describe it as the physical and emotional experience of gradually becoming weaker and letting go of their attachment to living.” Nurse

How will I know that the end is near?

For many, dying is a gradual shutting down of the body's systems. Energy levels fluctuate and there are good days along with days when you can't do much at all. Appetite reduces and sips of water or a teaspoon of food here and there may be enough.

As death gets closer, it's common to have little interest in talking and the outside world. You may find your attention withdrawing from family and friends, and you may sleep more and more during the day.

Near the end, many people slip into unconsciousness before dying, although some remain alert almost until the end. Others may have phases where they are awake and can talk, and then slip back into unconsciousness.

No-one knows how a dying person experiences the moment of death. Whatever happens, it is thought to be a peaceful moment.



Emotional and spiritual concerns

As you approach the end of life, you may grapple with how to talk about death and dying, and how to find hope and meaning. This chapter offers ideas for starting conversations, and navigating emotional and spiritual concerns.

Talking about dying

Most people are not used to talking openly about death and dying, and it's common to avoid this conversation.

Why it helps to talk

There may be days when you feel like talking about approaching the end of life, and days when you don't. It may even change from minute to minute. In general, it can help to discuss your fears and concerns about death with trusted family and friends. When you share how you think and feel with people you trust, it can often help support all of you through the sadness, anxiety and uncertainty.

Some people dying with cancer have said that the process can feel isolating and lonely, even with a stream of visitors. This is particularly true if family and friends avoid talking about what is happening. If you are comfortable with people acknowledging that you are dying from cancer, let them know.

When you don't want to talk

You may find that you don't want to talk about dying, or that you want to discuss it with some people but not others. You may be the type of person who would prefer to focus on making the most of the time you have left, rather than talking about death. In some cultures, people think it's disrespectful to talk about dying. Or they may feel that talking about death makes it happen sooner.

Everyone handles dying in their own way. If you don't want to talk about facing the end of life, your wishes should be respected.

The effect on people close to you

You may sometimes feel that the hardest part about dying is the effect it will have on your family and friends.

People living with terminal cancer often say family and friends react in a range of ways when they find out the disease is at the end stage. Different family members and friends may:

- offer to help in any way they can
- be overprotective, not wanting to leave you alone
- refuse to believe the prognosis, saying things like “I’m sure you’ll get better” or “You’ll beat this”, or suggest various forms of treatment
- volunteer the story of a friend or celebrity who experienced a miraculous recovery from something everyone had deemed hopeless and fatal
- pull away and withdraw from your life
- start to regard you as already gone.

Some of these reactions can be hurtful and frustrating, but they don’t mean that your family and friends don’t care. They need time to adjust to the news and come to terms with how they’re feeling. While you may be disappointed by the reactions of some people, you may also be surprised by how much support is offered and by who offers it.

“People saying ‘You’ll get well’ makes me really cross. I know I won’t get well. I want to say, ‘I am going to die and don’t you dare deny me this business of dying.’” Catherine

How to tell children

Telling children that you are dying will be confronting and difficult. There is no easy way to approach this conversation, but it is important to let them know what is happening. Like adults, children of all ages need time to prepare for the death of someone close to them. It's natural to want to protect children, but children will often sense that something has changed. Not sharing the prognosis can add to their anxiety – and yours.

How you tell your children will depend on their age, but these suggestions may help:

- It may be easier to have your partner or a support person with you when you have the initial discussion.
- Be honest with your children and explain the situation using straightforward words, such as 'dying' and 'death'. Avoid terms such as 'passed away', 'lost', 'went to sleep' or 'resting', which can be confusing or alarming for them.
- Keep your explanations as simple as possible, and be guided by their questions so you don't offer more information than they may want or can handle.
- Depending on their age, children may benefit from seeing a counsellor or play therapist.

For more information, call 13 11 20 for a free copy of *Talking to Kids About Cancer*, or visit your local Cancer Council website.

If you live alone

Many people with advanced cancer are elderly and live alone with limited support from family or friends. If you live alone and don't have a family member or friend who can act as your carer, you can seek assistance from other sources, including:

- the palliative care team
- your local community health service
- the local council
- a church or other religious group
- practical support services (see page 75)
- Cancer Council 13 11 20.

Palliative care providers and other services can help you maintain independence for as long as possible. At some point, however, you may need 24-hour care. This is usually available in a palliative care unit (hospice), hospital or residential aged care facility.

If you want 24-hour professional care to be provided in your own home, you will usually need to pay for private nursing services, which can cost many thousands of dollars. You may feel more in control of the situation if you investigate your options ahead of time and discuss your wishes with your health care team.

Coping with change and loss

Finding a way to cope with knowing you are dying can depend on many factors, including your age, whether or not you have children, your relationships with a partner or family, and your cultural or spiritual beliefs.

Everyone will find their own way at their own pace. There is no right or wrong way. For some, learning more about the physical dying process can make it easier to cope. Others find it helps not to think too far ahead, but instead to focus on a month, a week or even a day at a time.

“ If I didn’t wake up every morning hopeful, then I wouldn’t get out of bed, get dressed, eat or breathe. What’s anyone without hope? ”

Holly Webber, ‘Living with death’, The Observer, Sunday 19 June 2011

Finding hope

When you’ve been told that you’re dying with cancer, you may find it hard to feel hopeful. While it may be unrealistic to hope for a cure, you can find hope in other things, such as sharing some special times with those you love. Studies of people dying with cancer show that people’s hope can be maintained when their health professionals:

- involve them in decision-making, especially about palliative care treatment options and where they’d like to die
- reassure them that any pain and other symptoms will be well controlled.

Maintaining a sense of control

When people learn that they are approaching the end of life, they often feel like they’ve lost control. One way to maintain some control is to make decisions about your current and future medical treatment, and to tidy up unfinished business (see pages 42–53).

Finding a balance between knowing you are dying and still trying to live as fully as possible is sometimes called 'living with dying'. This may mean focusing more on the present. You may find that some days it's easier to achieve this than others.

Loss and grief

Other losses and changes happen throughout a terminal illness – loss of work, loss of social roles, loss of friendships, loss of connection to community, and loss of independence. A dying person often needs to spend time grieving for these losses.

You might also experience anticipatory grief, reacting to the impending loss of your life. People often grieve for events they won't be around for, such as marriages, graduations and having babies. People without children or a partner may mourn the lost opportunity to have these relationships or experiences.

Gradually, you may feel less able to do things or you may lose interest in activities you previously enjoyed. For many people, this is a natural part of coming to terms with death. It may make you feel sad and very low, but you may also move towards a sense of peace.

Spirituality at the end of life

Spirituality is an individual concept. For some people, it means being part of established religious beliefs and practices, such as Christianity, Judaism, Islam, Buddhism, or Indigenous belief systems. For others, spirituality is expressed as a personal philosophy or a worldview.

For many people at the end of life, spirituality is an important source of comfort and strength. Some people, however, find their beliefs are challenged by their situation. They may feel abandoned, and no longer find comfort and strength from their religion.

It may help to talk about your thoughts and feelings with a spiritual care practitioner (sometimes called a pastoral carer or chaplain). A spiritual care practitioner is part of the palliative care team and has the expertise to discuss spiritual issues, whatever your religion or even if you are atheist or agnostic. You may wish to discuss life's meaning or your beliefs about death. A spiritual care practitioner can also provide encouragement and companionship.

People often say that knowing they're dying makes them feel more spiritual, and they need to think about and discuss these issues. In some cases, they may embrace a belief system that they have never been interested in before or abandoned many years ago. Although many people do search for meaning at the end of their life, others are not interested in spirituality, and dying doesn't necessarily change that.

Some people find comfort in prayer or meditation, and gain support from knowing that other people are praying for them or sending positive thoughts their way. Many religions have specific practices for when people are dying. If you want to follow certain rites in a hospital or hospice, it's best to discuss this with the staff. They will be able to help find the space and time for you to do this, and your customs can often become part of your palliative care plan.



Physical concerns

Near the end of life, the focus of medical care is usually on maintaining your quality of life, and making sure that pain and other symptoms are well controlled. This chapter describes the common symptoms experienced towards the end of life and how they can be managed.

Symptoms at the end of life

As cancer progresses, it can cause a range of symptoms. People who are dying, and their families and carers, often worry about how these symptoms will be managed. The health professionals in your palliative care team (see pages 14–15) will work to provide you with the highest possible level of comfort and care during your last days. Ask them any questions you have if you would like to have a good understanding of what to expect.

Pain

Many people with end-stage cancer worry they could spend their final days in pain, but not everyone with cancer has pain. If you do, the health professionals caring for you will help you control the pain as much as possible.

Everyone experiences pain differently, so it might take time to find the right pain treatments for you. Controlling the pain may allow you to continue with activities you enjoy for some time and offer a better quality of life. Even if you have experienced pain from cancer, it will not necessarily get worse as you get closer to dying.

The right pain relief for you depends on the type of pain you have and how intense it is. You might be offered:

- mild pain medicine, such as paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs)
- moderate pain medicine, such as codeine
- strong pain medicine, such as morphine, oxycodone, hydromorphone and fentanyl.

You may also be given other types of medicine along with the main pain medicine. These could include:

- antidepressants and anticonvulsants for nerve pain
- local anaesthetics for nerve pain
- anti-anxiety drugs for muscle spasms
- a nerve block or epidurals (for pain that is difficult to manage).

Palliative care specialists are highly experienced in the management of pain and won't let you be in unrelieved pain. Some people worry about becoming addicted to pain medicine, but this is not a concern with end-stage cancer.

For more information, read Cancer Council's *Overcoming Cancer Pain* booklet – call 13 11 20 for a free copy or download a digital version from your local Cancer Council website.

Help from family and friends

This is the time to let your family and friends help you. People often want to help in whatever way they can, so accept their assistance if they offer. If you want to complete a specific task, invite family members or friends to help, or make a list of tasks you'd like their assistance with.

You might like to ask one person to coordinate offers of help, or you could use a website such as lovlist.org or caringbridge.org. These websites allow members of your social circle to sign up for tasks you nominate and simplify the process of organising assistance.

Tiredness and fatigue

Having a terminal illness will almost certainly leave you feeling fatigued. Try to pace yourself and save your energy for the activities that are most important to you.

The fatigue may affect your ability to think clearly and feel confident about making decisions. This can be frustrating, particularly when you are dealing with the practical concerns outlined on pages 42–53. If you are trying to put your affairs in order for family members, you may want to do this at a time of day when you have more energy.

Some people sleep a lot at the end of life, but others may struggle with sleep disturbance, which can make fatigue worse. If you find it hard to sleep, it may be because of anxiety, pain or a side effect of a medicine you are taking. In any case, let your palliative care team know, as they may be able to adjust your medicines or offer another medicine to help you sleep. They may also suggest complementary therapies such as meditation and relaxation. Improving the quality of your sleep will improve the quality of your waking hours.

Loss of appetite

Many people find they do not feel like eating as they near the end of life. This loss of appetite may be because of other symptoms, such as pain, nausea, constipation or breathlessness, or because the body's energy needs have slowed down and it's no longer necessary to eat as much.

You don't have to force yourself to eat – eating more than you feel like may only make you uncomfortable, and can cause vomiting and stomach pain. Try having small meals or eating your favourite foods more frequently. Another option is liquid meals. Ask your doctor, nurse or dietitian to recommend something suitable.

It's common for others to want to encourage you to eat, as preparing food for you is how they show they care. You may need to let them know that you don't feel like eating, and suggest other ways they can show their love, such as by giving you a hand or foot massage or reading aloud to you.

As the disease progresses, the body reaches a point where it can no longer absorb or get nutrients from food. Clear fluids such as water or weak tea may be all you can handle. There will come a time when even this isn't tolerated, and family or friends can help keep your mouth moist. See *How you can help in the final stages* on pages 62–63 for ways others can offer comfort.

Feeling sick

You may feel sick or have trouble keeping food down, either because of the cancer or because of side effects from medicines you're taking. Nausea and vomiting can usually be managed with medication. Anti-nausea medicines (anti-emetics) can be taken as tablets or, if swallowing is difficult, as wafers that dissolve on the tongue, as injections under the skin, or as suppositories, which are inserted into the bottom and absorbed through the lining of the rectum.

Shortness of breath

Breathlessness, also called dyspnoea, is common at the end of life. Breathing may become uneven, change rhythm, and become noisy. Your palliative care team will assess if something is causing the dyspnoea and manage it with medicine or practical measures, such as being placed near an open window, having a fan in the room or trying relaxation exercises. Adjusting your position in bed or sitting up slightly can also help.

Feeling breathless may make you feel distressed and anxious, and this is likely to make the breathlessness worse. Talk to your doctor about medicines that can ease your anxiety.

Other symptoms

As you approach the final days or hours of life, various symptoms can occur as the body's systems start shutting down. These may affect breathing, bladder and bowel function, and behaviour. Such symptoms can be managed to help you feel more comfortable.

It is natural to feel concerned about others witnessing some of these physical changes. However, the changes are a normal part of the dying process. Your medical team understand this and can help explain what is happening to your family and friends.

Some people find it reassuring to know more about what might happen in the last stages, when they may no longer be fully conscious, but others find it distressing. If you would like to know more, see pages 64–67.

Thoughts about euthanasia

If an illness is prolonged or very debilitating, some people think about speeding things up. Euthanasia is when somebody's life is deliberately ended to relieve them of their suffering from an incurable condition or illness. Physician-assisted suicide is when a person ends their own life with the help of a doctor.

In 2016, both euthanasia and physician-assisted suicide were illegal in every state and territory in Australia. There is currently much discussion of these issues, and the laws are under review in some places (visit end-of-life.qut.edu.au for updates). Regardless of the law, some seriously ill people consider this path.

Sometimes a person with cancer may decide that they want their death hastened, but later decide that they don't. They may have thought that way because they were

feeling particularly ill, scared or worried about the strain they were putting on others.

If this is how you feel, discuss your concerns with a doctor, counsellor or social worker. Sometimes these feelings are due to depression or a sense of helplessness, or because pain or other symptoms are not being well controlled.

Pain and depression can almost always be treated, and help is generally available for other symptoms. It is important that you talk to your doctor or nurse about any physical or emotional symptoms that are causing you pain or distress, and find ways to make your final days more comfortable.

If you urgently need somebody to talk to because you are thinking about ending your life, call Lifeline on **13 11 14** for free, confidential telephone counselling at any time.



Where to die

Choosing where you would like to die is a personal decision. This chapter describes the options of dying in your own home, in a palliative care unit or hospice, in hospital, or in a residential aged care facility. Each option has pros and cons.

Making your choice

Choosing where to die can be a confusing and difficult decision to make. The options include:

- your own home
- a palliative care unit or hospice
- a hospital
- a residential aged care facility.

Having some control over where death occurs is often cited as a key factor in dying well, but where that place might be will be different for everyone. As well as your own preferences, you'll need to evaluate your physical needs and the support that can be provided by family and friends.

Discuss with your family, friends and health care team where you would like to have end-of-life care and what is important to you. Find out their views and preferences. Having these conversations as early as possible and planning ahead can increase the chances of care being able to be provided in your place of choice.

In some cases, you may feel like your choice is limited, and that the practicalities help decide the setting. This may be because you have medical needs that only a hospital or palliative care unit (hospice) can meet, or you may live in an area too remote for home visits. Your house may be unsuitable, perhaps because of stairs or a small bathroom, or you may not have any family or friends in a position to provide care for you at home. Talk to the palliative care team about your concerns and find out what options are available in your area.

What if you change your mind?

Where you would like to die may change over time and as your circumstances change. This is understandable and your wishes should be respected whenever possible. You may need to have ongoing conversations with your carers and medical team about the best place for your care.

In your own home

If asked, many people say they want to die at home around familiar surroundings and people. While it is not for everyone, if you do want to be at home, help and support may be available for you and your carers. Even if you live alone, with planning you can stay as long as possible in your own home.

Although dying is a natural process, few people have experience or knowledge of looking after someone who is dying. It's a good idea to check how your family and friends feel about home care, and to allow them to express their own wishes without being judged.

Some carers may appreciate having you nearby and not having to fit in with the hospital routines. Other carers may be frightened and worried that they don't know what to do. For some people, the thought of living in or visiting a house where someone has died fills them with concern.

Caring for someone who is dying at home can be a meaningful and comforting experience, but it can also have challenges. Your GP, nurse or specialist palliative care team can let your family

know what assistance is available, and reassure them that they don't have to cope alone. You might ask people you know who have cared for someone dying at home before to share their experience with you. Your carers can also read the *Caring for someone nearing the end of life* chapter on pages 54–72.

Sometimes people go into a hospice or hospital to have their symptoms managed, or to give their carers a break (respite), and then return home. Or they may decide that they would be more comfortable in the hospice or hospital. Accept that plans can change and do what is best for your particular situation.

If you are planning to die at home, talk to your palliative care team about ways of dealing with unexpected medical events. Keep a list of phone numbers to call if you need advice and support.

Home: what are the benefits?

- Helps you maintain emotional wellbeing by being cared for in a familiar environment surrounded by people you know well.
- Lets you spend more time with family and friends.
- May offer more opportunities to maximise quality of life.
- May feel more natural and less clinical, while still giving you access to expert medical advice and symptom control.
- Allows you a sense of control over the last part of your life.
- Your family and friends may find comfort in providing most of your care.



In a palliative care unit or hospice

You may decide that you'd be more comfortable in a setting with staff who have the expertise to help your family and friends look after you. Specialised palliative care facilities may be called palliative care units (often associated with a hospital) or hospices. They focus on end-of-life care centred on quality of life. Staff specialise in providing physical and emotional comfort to the patient, and supporting the family before and after the death.

Palliative care units and hospices are different from most hospital wards. Usually quieter and calmer, they have a more homely environment. Many people value the relaxed surroundings, as well as the skilled staff and expert symptom management.

These facilities often offer short-term 'respite' care as well as longer-term care for the dying person. Sometimes you can go back and forth during your final weeks. Many now have a maximum length of stay, so you may want to check this with them ahead of time.

A palliative care unit or hospice may offer a break from mainstream health care or from people wanting to visit you at home. You may choose this option if you want to relieve your family from caring for you while dying, although they can still be involved. They can help in many ways, such as feeding, bathing, and offering comfort by reading, sharing music or simply being present.

Some people and their family and friends are unsure of when to contact a palliative care facility. They may wait to call until the final days, possibly missing out on the support that this



Palliative care unit or hospice: what are the benefits?

- A warm and comfortable physical environment.
- 24-hour care with expert pain and symptom control.
- Focus is on quality not length of life.
- Direct access to a team of professionals and volunteers trained to meet the needs of the dying patient and carers.
- Allows the patient and their family and friends to focus on being together.
- Carers can leave at the end of the day and get some rest.
- Some families prefer not to live in a house where someone has died (although others find this a comfort).

environment has to offer. Some facilities have waiting lists, so talk to your palliative care team about when would be an appropriate time to make the initial contact.

In hospital

Even when death is expected, more people approaching the end of life die in hospital than anywhere else. While some people feel more secure being near health professionals, others feel anxious about hospital care, believing it will be too impersonal.

If you have spent a lot of time in hospital during your illness, you may want to stay on the same ward where you are familiar with staff and surroundings, and they know you and understand your specific needs. You'll need to check if this is possible – sometimes people are moved to a different ward as their medical needs change.

To help create a more homely environment, ask if you or your carers can bring in familiar items from home, such as a favourite blanket or photos.

Hospitals sometimes provide medical interventions, such as resuscitation and intravenous lines, that may not be what you want in the final weeks or days of life. Your health care team should work with you to make sure your care plan matches your wishes. If you are concerned, talk to the hospital staff and request that you don't receive such interventions. You can arrange to have your wishes recorded in a do-not-resuscitate (DNR) order or other document before an emergency occurs.

The quality of end-of-life care in a hospital can be managed with communication and advance care planning. Preparing an advance care directive can help give you control over the type of medical treatment you receive. See page 50 for further details on what this is and how it can help ensure your wishes are followed.



Hospital: what are the benefits?

- Experienced medical and nursing staff are available at short notice to manage physical symptoms (e.g. pain, fatigue, breathlessness) and emotional needs (e.g. anxiety, delirium, agitation).
- Carers can leave at the end of the day and go home to get some rest.
- 24-hour care.
- Some families prefer not to live in a house where someone has died.

In a residential aged care facility

A residential aged care facility (formerly called a nursing home) is a place where people stay who need continual care and help with daily living. These facilities cater for people with a range of chronic conditions, and nurses and aides are available 24 hours a day to provide care. Some aged care facilities provide respite and hospice care also.

Some people fear that dying in residential aged care will be unpleasant and perhaps frightening. Yet dying in an aged care facility can be comforting, particularly if it has been your home for a period of time and you are familiar with the staff, who will try to create the right environment to make you comfortable.

If you want to die in a residential aged care facility, ensure that you have an advance care directive (see page 50) in place. Talk to your care providers about avoiding an unnecessary transfer to hospital at the end of life.



Residential aged care facility: what are the benefits?

- A less clinical environment than some hospitals.
- Experienced staff to manage symptoms and needs.
- May be located close to carers, family or friends.
- Carers can leave at the end of the day and go home to get some rest.
- Some families prefer not to live in a house where someone has died.



Practical concerns

Getting your affairs in order can be an important task in the final stages of life. This chapter explains the purpose of advance care planning, and discusses medical, legal and other practical issues to consider at this time.

Planning for the end of life

Planning for the end of life can be both rewarding and difficult. For many people, preparing for death helps them feel more in control of their situation. Some may wish to ease the burden on family members or friends. Making arrangements can also give you a sense of relief that the people, possessions and causes that mean something to you will be looked after in the future.

Organising your paperwork

Having all of your paperwork up to date and in one place will make it easier if a family member has to help you with financial and legal matters. Important documents might include:

- birth, marriage, divorce and citizenship certificates
- bank and credit card information
- investment details (e.g. shares, funds)
- Centrelink and Medicare details
- list of social media and other online accounts (see page 49)
- superannuation and insurance information
- loan details (e.g. house, car) and house title/lease documents
- passport
- will
- document appointing a substitute decision-maker (see page 49)
- advance care directive (see page 50)
- funeral information.

It's a good idea to check or update who you've nominated as beneficiaries on your retirement plans and life insurance policies. Let someone close know how to contact your lawyer.

Getting your affairs in order – what to consider



Financial/legal matters

- Have you arranged your financial affairs?
- Do you want someone to make legal or financial decisions for you if you are not able to?
- Does someone know where to find important papers?
- Do you have a valid will?
- If you have life insurance, is the beneficiary information up to date?
- If you have superannuation, have you nominated a beneficiary? If it is a 'lapsing' nomination, you must confirm it in writing every three years, so check when you did this last.



Relationships

- Have you prepared letters for family or friends, if you'd like to do so?
- Who would you like to have around you as you get closer to death? Are there people you don't want around?
- Are there unresolved issues that you would like to sort out with particular people?
- Have you left instructions and passwords for your social media accounts?



Medical care

- Are there certain treatments that you don't want to have?
- Have you discussed your wishes for end-of-life care with your family, carers and health professionals?
- Have you considered who can make decisions about your end-of-life care if you're not able to make them yourself?
- Have you recorded your wishes for future medical care in an advance care directive or appointed a substitute decision-maker?



Spiritual issues

- Are there any cultural, spiritual or religious practices that you would like carried out before or at the time of your death, or once you have died? Who do you need to ask to make sure this happens?
- Do you want a minister, priest, rabbi, imam or another spiritual adviser present at the end?
- Do you want to be buried or cremated? Do you have a burial plot? Would you like your ashes scattered in a particular place?
- What are your preferences for a memorial service? Have you shared your wishes?

“ I feel like I have a window of time to get my house in order. I want my transition to be easy for my family. ” Pat

Advance care planning

If you have not already done so, it is important to think about your wishes for your future medical care, and to discuss these with your family, friends and health care team. This process is called advance care planning.

Although advance care planning is often done when people are told their condition is terminal, or as they approach the end of life, it can be started at any stage, whether you are healthy or ill.

As it is hard to know what medical care you're going to want until the situation arises, uncertainty is common. Many people find their attitudes and preferences for medical care change as they get closer to death, and they need to revisit their decision regularly. To help you decide, think about what is important to you and talk with your health professionals, over several appointments if necessary.

For some people, quality of life is more important than length, but for others, it may be the reverse. Some people may feel there's nothing worse than death, and will do anything to avoid it, while others prefer to die comfortably without unnecessary and sometimes uncomfortable interventions. You may want to find a balance between what medical care can achieve and the side effects of treatments.

Discussing these issues with the people around you will help them understand your goals, values and beliefs, and help to ensure that your wishes are respected should you lose the capacity to make your own decisions. Without these conversations, it's not uncommon for distressed family members to have disagreements about whether to keep you alive using any means possible or focus on your quality of life. Palliative Care Australia have developed a discussion starter that can help you reflect on your preferences for care and talk about them to your family – visit dyingtotalk.org.au/discussion-starter.

As part of your advance care planning, you may appoint a substitute decision-maker and record your wishes in an advance care plan and/or advance care directive. See pages 49–50 for more information about these documents.

To find out more about the process of advance care planning, visit advancecareplanning.org.au or call the national advance care planning advisory line on 1300 208 582. Palliative Care Australia also has useful information on their website at palliativecare.org.au/advance-care-planning.



The law at end of life is complex and can be confusing. The Australian Centre for Health Law Research has prepared the End of Life Law in Australia website. This website provides detailed information about Australian laws relating to death, dying and end-of-life decision-making. Visit end-of-life.qut.edu.au to find out more.

Preparing legal documents

If you have not already done so, now is the time to think about making a will, appointing a substitute decision-maker, and preparing an advance care directive.

For any of these documents to be legally binding, you need to have capacity at the time of signing the document. Capacity includes the ability to understand the choices that are available and the consequences of your decisions, and the ability to communicate your choices. If there could be any doubt about your capacity, talk to both your lawyer and your doctor about this.

Making a will

A will is a legal document that records who you would like to receive your assets (estate) after you die. A will may also record your wishes regarding guardianship of your children.

Many people want to make a will or update the one they have as their circumstances change. Making a will is not difficult but it needs to be prepared and written in the right way to be legally valid. It is best to ask a lawyer to help you or contact the Public Trustee in your state or territory. For more information on preparing a will, visit your local Cancer Council website or call 13 11 20.

When you die without a valid will, you are said to die intestate. This can make matters complicated, lengthy and expensive. A court appoints an administrator to arrange your funeral and then distribute your assets to family members according to a formula. If there are no eligible relatives, your assets go to the state.

Although any will can be challenged in court, having a valid will usually means your assets will go to the people of your choice, avoids extra expenses, and simplifies the process for your family.

Appointing a substitute decision-maker

You can appoint someone to make decisions for you if at some point in the future you're not able to make them yourself. These can include decisions about your finances, property, medical care and lifestyle. This person, called a substitute decision-maker, should be someone you trust, who will listen to and understand your values and wishes for future care. Depending on which state or territory you live in, the documents used to appoint a substitute decision-maker may be known as an enduring power of attorney, enduring power of guardianship, or appointment of enduring guardian.

Managing your digital legacy

If you use social media, such as Facebook, Twitter and Instagram, you will need to think about what happens to your accounts after your death. Each social media platform has different rules for deactivating accounts, while some allow your account to be turned into a memorial page. It is a good idea to leave a list of all your

accounts, passwords and instructions with someone you trust, so they can manage your ongoing digital presence according to your wishes.

Palliative Care Australia has produced a *Guide to a Social Media Afterlife*. You can find it at palliativecare.org.au/resources.

Advance care directive

You can record your wishes for your future medical care in an advance care directive, commonly known as a 'living will'. This provides a record for doctors, family and carers to consider, and may be legally binding in some states and territories. Depending on where you live, the advance care directive may have a different name, such as a health direction, advance personal plan, advance health directive, or refusal of treatment certificate.

Keep a copy of your advance care directive for yourself and also give copies to your GP, oncologist, substitute decision-maker and solicitor. Ask your doctor or the hospital to place the directive on your medical record. You can also upload a digital version to My Health Record, a government website that stores your health information – find out more at myhealthrecord.gov.au.

For more information, visit your local Cancer Council website and read the *Getting your affairs in order* fact sheet, or call 13 11 20 to check whether a printed version is available. Legal advice is also recommended. Cancer Council's Legal Referral Service can connect you with a lawyer and arrange free assistance for eligible clients.



Some people with cancer may be able to donate their organs after they've died. This will depend on the cancer's type and spread and will be assessed by a doctor after the death. To record your wish to donate organs, visit donatelife.gov.au. Share your decision with family as they will be asked to give consent after your death.

Planning your funeral

Some people may find planning their own funeral difficult or morbid, while others may be comforted that it will be carried out according to their wishes and that their family or friends won't have to guess what they would have wanted. Still others think that funerals are for the family, and should be organised by them. Some people decide they don't want a funeral at all. This is a valid choice, but one that is worth discussing with your family and friends ahead of time.

Most people do have a funeral of some sort. It is probably not easy for most of us to hear or think about funerals. However, there can be a satisfaction in leaving your mark on the occasion, and also involving your family in the planning. If you feel you need to make preparations but you can't do the work, or prefer not to, talk to a social worker or spiritual care practitioner who can help you.

You might simply discuss your wishes with your family, or you can record them in writing or lodge a plan with a funeral director of your choice. There are no rules. You can personalise your funeral to meet your cultural or spiritual preferences. You may just have a few simple requests for music you want played or poems you'd like read, or you may have detailed plans for the full service.

To prearrange or prepay a funeral, talk to a funeral director. You can find a *Plan a Funeral Form* on the Australian Funeral Directors Association website at afda.org.au. Copies of a prepaid funeral contract should be provided to members of your family or filed with your will. If the funeral is not prepaid, payment is made once the service is conducted.

Saying goodbye

Knowing you will die offers you a special opportunity: the chance to say goodbye to those you love and care about. It is a sad and difficult thing to do, but some people say they feel lucky that they've had the time to prepare.

Saying goodbye is a personal experience and you need to do what is right for you. When you feel you are ready, consider how you will say goodbye. You might set aside a time to talk to each person individually. Or, if you are physically up to it, you might have a gathering for friends and family. Other ways to say goodbye include writing letters, creating a recording on CD or DVD, and passing along keepsakes. You can find a range of other suggestions in the book *Dying to Know: bringing death to life* by Andrew Anastasios.¹

“When I have been up to it, my family has been filming a video of our time together, especially the special moments with my grandchild. This has been very important to me, and will be a treasured keepsake for my family.” Agnes

If you have children or grandchildren, you may want to write them a letter or make them a recording. You could specify that this is to be given to them at a specific age or time in their life. You (or your friends) could also create a slideshow or scrapbook of special photos, or use an online service such as itsaboutus.com.au. A memory box (see opposite) can be another special keepsake for

your family. You may find it hard to think about a time when you won't be there for your children, but these measures can be helpful and comforting for children. If your children are very young, they'll understand your words and sentiments when they're older.

Leaving an 'emotional will'

An 'emotional will' is a document that shares your thoughts with and shows your concern for your family and friends, and even future generations. It is not a legal document and can be presented as creatively as you wish. You might want to record insights, requests, thanks, advice, memories or anything else that is important to you. For more information, you can download the Groundswell Project's *Emotional Will and Death Checklist* from thegroundswellproject.com/10-things-workshops.

Making a memory box

A memory box is a collection of keepsakes for your family. What you put into a memory box will be personal choices, but some possibilities include a:

- treasured photo
- DVD of a family event
- special birthday card
- favourite cap, tie, scarf or another item of clothing
- list of shared memories
- lock of hair
- family recipe
- pressed flower from your garden
- bottle of your favourite perfume or aftershave.



Caring for someone nearing the end of life

Even when you know the end of life is approaching for a family member or friend, you might not feel prepared. This chapter covers the practical, emotional and physical issues to expect, and how you can provide comfort and support.

Coping as a carer

Looking after a person who is dying can be stressful, and you will need help and support. It's not unusual to feel like you don't know what to do, what to say and how to cope. If you've never been around someone who is dying before, you may be afraid of what will happen. Learning about what might happen can help you feel less frightened and confused, and allow you to prepare for the emotional and physical changes ahead.

Caring can be physically and emotionally hard work. Cancer Council's *Caring for Someone with Cancer* booklet has many suggestions on how you can look after yourself during this time. Call 13 11 20 for a free copy, or download a digital version from your local Cancer Council website.

Providing practical support

Many people worry about how they'll manage with the day-to-day tasks of looking after someone. These might include showering, toileting and getting the person safely in and out of bed. You may find providing personal care awkward or embarrassing, especially at first, but most carers say they get used to it. However, your family member or friend may prefer to receive personal care from somebody they don't know well.

The palliative care team (see pages 12–15) is there to support you as well and may be able to take over some of these tasks. This support can help reduce your stress and free you up to spend quality time with the person you're caring for.

Ways to help

There are many things that family and friends can do to help support someone at the end of life.



Prepare meals

Preparing meals for someone who is sick can become complicated as their needs and illness change. Try cooking simple, small meals. You may have to mash food so it's easier to swallow – the palliative care team will have a dietitian who can advise you on what is needed. As the disease progresses, the person may lose their appetite and not be able to eat or drink. At this time, it's important not to force eating or drinking. If the person cannot drink, chips of ice can help to moisten the mouth.

Do odd jobs and run errands

Friends can offer to step in with walking the dog, mowing the lawn, picking up the kids or doing the shopping – anything that eases the workload of the main carer.



Sort out the paperwork

For many people who are dying, getting their affairs in order can help them feel like they've given closure to their life. You can help gather important documents, discuss the person's choices for their future health care, and arrange legal advice if needed.

Assist with toileting

You may have to help the person get on and off the toilet or commode, help them use urine bottles or bed pans if they can't get out of bed, and sometimes help them to wipe themselves. Lifting someone is hard work and you may need help with this, either from another person or mobility aids or equipment. An occupational therapist can help you choose suitable equipment.



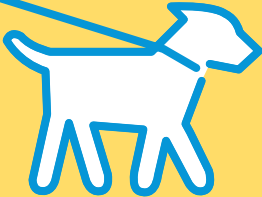
Help with bathing and washing

If the person you are caring for can't move around easily, you may have to sponge bathe them or wash their hair over a basin.



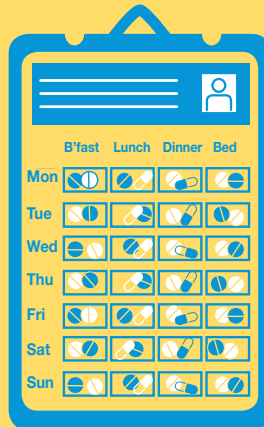
Help with getting in and out of bed

It's common for a dying person to spend more time in bed. You may need to help them get in and out of bed, roll them over regularly so they don't get bedsores, or lift them to change the sheets. You can use equipment to help with lifting. Many people create space in the living room for the bed, particularly if bedrooms are located upstairs. The palliative care team can help you provide this care and arrange equipment such as a hospital bed.



Manage medicines

If you need to give medicines and feel overwhelmed, ask your doctor, pharmacist or nurses for suggestions. For tablets and capsules, a blister pack (e.g. Webster-pak) can set out all the doses that need to be taken throughout the week. Cancer Council's *Caring for Someone with Cancer* booklet includes tips for managing medicines.



Record social media details

People often have more of a social media presence than they realise. You can help the person work out which social media accounts they have and what they want to happen to these accounts after they die, and then help compile a list of passwords and instructions.

Providing emotional support

The diagnosis of a terminal illness may create a crisis situation for family and friends. How everyone responds may depend on their relationship with the person dying and their own beliefs about death. It is natural to feel shocked, angry, scared, sad or relieved, or a combination of these emotions.

You may be worried about discussing the end of life with the person who is dying because you think you'll upset them. It may be helpful to know that people who are dying often want to talk about what is happening but are afraid the topic will upset their carer, family member or friend. Starting the conversation can be difficult, but the opportunity to share feelings can be valuable for both of you.

As the person you are caring for nears the final days of life, there are still many ways to spend time together: you can read a book; sing a song; talk about what you've been doing or about the weather; share some special memory or experiences you've had together; or tell them that you love them and that family send their love. If you find conversation difficult, see the suggestions in *When you don't know what to say* on the facing page.

You may find yourself wishing for the person's life to be over. It's also not unusual to start thinking about yourself – about other events in your life, the funeral, and so on. All of these responses and thoughts are natural and okay. It may help to speak to a health professional or counsellor about your feelings, or to call Cancer Council 13 11 20.

Saying goodbye

A life-limiting illness offers you time to say goodbye. You can encourage the person dying to share their feelings, and you can share your own in return. Sharing how you both feel can start important conversations, which can be memorable. This is also an opportunity for you to tell the person who is dying what they mean to you, and how you might remember them.

The person nearing the end of life may want to make a legacy, such as documenting their life or writing letters to family and friends. They may want to visit a special place or contact someone they've lost touch with. These tasks are all things you can help the person do. They are all part of the process of saying goodbye, for all of you.

When you don't know what to say

People often wonder what they should say to a person who is dying. It's understandable that you don't know what to say – what you feel might be so complex that it's hard to find the right words, or any words at all. It is common to worry about saying the wrong thing.

You may want to say something that would help them cope but don't know what that is. It's usually better to say something than pretend that nothing is wrong.

Someone who is dying will probably appreciate knowing that family and friends are thinking of them. Even if you feel you're not doing anything, your presence sends the message that you care.

In her book *The Etiquette of Illness*², Sue Halpern suggests asking, “Do you want to talk about how you’re feeling?” rather than “How are you feeling?” This approach is less intrusive and demanding. It also allows the person the choice to respond or to say no.

- Listen to what the person dying tells you. They may want to talk about dying, their fears or plans. Try not to prompt an answer that confirms what you think or your hope that things could be better. If you think they’d find it easier to talk to a spiritual care practitioner, offer to put them in touch with one.
- Try to treat someone who is dying as normally as possible, and chat about what’s happening in your life. This makes it clear that they’re still a part of your life.
- Avoid talking with an overly optimistic attitude, for example, by saying “You’ll be up in no time.” Such comments block the possibility of discussing how they’re really feeling – their anger, fears, faith and so on.
- Apologise if you think you’ve said the wrong thing.
- Let them know if you feel uncomfortable. They might be feeling uncomfortable too. It’s okay to say you don’t know what to say.
- Ask questions. Depending on how comfortable you feel asking direct questions and on their willingness to talk, you may ask, “Are you frightened of dying?” or you may prefer a softer approach, “I wonder whether there’s something you want to talk about?”

- Just be there. You don't need to talk all the time. Sometimes it's the companionship that is most appreciated – sit together and watch television or read.
- Encourage them to talk about their life, if they're able to and interested. Talking about memories can help affirm that their life mattered and that they'll be remembered.
- Accept that you or the person dying may cry or express anger. These are natural responses to a distressing situation.
- Even if they've shown no religious interest in the past, that could change as death approaches. You could offer to pray together, but respect their wishes if this is not something they want.

Keeping vigil

For many people, staying with the dying person is a way to show support and love. This is called keeping a vigil. You can simply sit with the person, perhaps holding hands. Hearing is said to be the last sense to go, so you may want to talk, read aloud, sing or play music. Your cultural or spiritual traditions may require someone to be present, and this may also be the time to perform any rituals.

Some people find keeping vigil exhausting and draining, and it can be hard to estimate how long it will last. Plan to take breaks or organise shifts with other family members and friends. You may worry that leaving the room could mean missing the moment of death. If this happens, it may be reassuring to know that sometimes a person seems to wait to be alone before they die.

How you can help in the final stages

Wherever someone chooses to die, family and friends can provide general care and comfort in the final stages. If you are providing care at home, ask for help from your palliative care team or other organisations (see pages 73–77). In a palliative care unit, hospital or residential aged care facility, ask the staff how you can be involved.



Atmosphere

- Use soft lighting.
- Have their favourite music playing in the background to create a gentle and peaceful atmosphere.
- Quietly read a favourite poem, passage from a book, or spiritual or religious text.



Comfort

- Apply lip balm to dry lips, and keep the mouth moist with ice cubes.
- Add incontinence sheets under the bed sheets.
- Use a vaporiser in the room.
- Keep the person warm with a blanket and use cushions to make them more comfortable.
- Help the person change positions frequently.



Gentle presence

- Sit with the person and talk or hold their hand. Often just being there is all that is needed so that they don't feel alone.
- Gently massage their hands or feet with a non-alcohol-based lotion.
- Don't force-feed even though you may be distressed by their loss of interest in eating.
- Speak gently, and occasionally remind the person of the time, place and who is with them.

Making arrangements

As death approaches, speak to the palliative care team about what to expect. You may want to consider various arrangements.



Rituals

Ask the person whether a clergy member or other spiritual leader should be at the bedside and what rituals or ceremonies are important to perform.



Contact list

Ask the person who they would like to have visit in the final days and who to call after the death.

Funeral home

Notify the chosen funeral home that a death is expected soon. Some people want to keep vigil after the person has died – you can have the body at home for up to five days, so let the funeral home know if this is your wish.



Ceremony

Find out what the person would like done with their body after death. Some people have strong views about whether they want to be buried or cremated, what sort of ceremony they want, and what type of memorial they would like.

Ambulance service

Ask your health professionals who to contact if complications arise at home. Your first reaction might be to call an ambulance, but an ambulance officer's duty of care may mean they have to resuscitate. If this is something the person you are caring for would prefer didn't happen, it's worth thinking about other options. You can also contact the ambulance service in your state or territory to find out if you can arrange a document so they are not compelled to resuscitate.



Providing physical support

When a person is dying, carers often have lots of questions: Can they hear me? Are they in pain? What can I do to make this easier? How long will it be now?

There will probably be gradual changes. Some people can continue with their activities, others find they have to pace themselves or spend more time at home. It can be upsetting to witness physical changes. It may help to know that they are part of the dying process, and don't mean that the person is distressed or uncomfortable.

You don't have to face these changes alone. The palliative care team (see pages 12–15) can help you provide physical, emotional, and practical comfort. You can call Cancer Council 13 11 20 to find out what support is available.

Changes that occur before death

Some family and friends find that information about the physical process of dying helps them prepare. Others prefer to take one day at a time and ask health professionals for explanations as the need arises. If you would like to know what to expect, this section describes the physical changes in the last days and hours of life.

Each death is unique, but as a person nears the end of life they often show common signs. In medical terms, the dying process is viewed as the body's systems closing down.

Sleeping more – The dying person has less energy, often spending most of the day sleeping or resting.

Loss of appetite – The body needs less energy to keep going and appetite decreases. The person may begin to resist or refuse meals or liquids, and weight loss can occur.

Little interest in the outside world – The dying person may gradually lose interest in those nearby. They may find it hard to concentrate and stop talking. Withdrawing is part of letting go. Near the end, some people have a sudden burst of alert behaviour.

Breathing changes – Breath intakes and exhalations often become rattly, irregular and laboured. You may hear a pattern of breathing known as Cheyne-Stokes: a loud, deep inhalation followed by a pause of not breathing (which may last from five seconds to as long as a minute), before a loud, deep breath resumes and again slowly fades out. Sometimes excessive secretions create loud, gurgling inhalations and exhalations, which some people call a ‘death rattle’. Various medicines can help dry up new production of secretions but not what is already there; however, it is thought that this breathing pattern is not painful.

Bladder and bowel changes – As the body’s systems slow down, the person may have trouble emptying the bladder, so a nurse or doctor may need to insert a catheter into the bladder to drain the urine and avoid a blockage. The doctor can also prescribe medicine to help with constipation, a common side effect of some pain medicines. As the person eats and drinks less, they will produce less urine and faeces. Loss of bladder and bowel control may happen in the last stages of the dying process, but not always. Special disposable incontinence sheets can be used.

Disorientation and confusion – Carers are often unprepared for the delirium that can occur in people who are dying. This delirium can involve a lower level of consciousness; memory loss; hallucinations (seeing or hearing things that aren't there) and delusions (false beliefs); mood swings; and sleep disturbances. A person who is dying may not be aware of where they are or who else is in the room, may speak or reply less often, or may respond to people who can't be seen by others in the room. The person may drift in and out of consciousness and possibly enter a coma.

Delirium may occur when waste chemicals (toxins) build up in the brain as vital organs begin to shut down, but it can also have a range of other causes, such as fever or constipation. Talk to the palliative care team about how the delirium can be controlled.

Restless moving, twitching, groaning or calling out – These symptoms are part of terminal restlessness, a type of delirium that may include agitation, anxiety, anguish and anger, all of which can be very distressing for carers. However, these symptoms are common and not necessarily uncomfortable for the dying person.

Cool skin, especially the hands and feet – As circulation slows down, the hands, feet, fingers and toes (the extremities) become cooler and turn a bluish colour. It's thought that the person will be unaware of feeling cold.

Dry mouth and dry or cracked lips – This can happen if the person is dehydrated or has been breathing through their mouth, or it may be due to some medicines.

Choosing the moment to die

Sometimes people appear to pick the moment to die. You may have heard stories of some people holding out until a particular relative or friend arrives at their bedside, or until a special occasion occurs, before dying. Others appear to wait until their family or friends have left the room before they die.

It can be difficult if you've been sitting with someone for many days, and they die while you are taking a break. You may feel guilty or regretful for not being there for them at that crucial moment, but it's a fairly common occurrence.

What happens at death

No-one really knows what death feels like, but we know what death looks like from those who have nursed a dying relative or friend. The person's breathing will cease, although they may stop breathing for a time and then take one or two final breaths. As soon as the heart stops beating, the body rapidly cools down and takes on a pale appearance.

The moment of death is sometimes described as being peaceful. Many carers say it was a profoundly moving experience and it felt like a privilege to be there. The memory of the final moments are likely to stay with you for a long time.

“ We had all surrounded my father-in-law's bedside, then we started to share the vigil in turns. When there were fewer people around, he passed away. ” Judith

After the death

Even when death is expected, it's common to feel upset, sad or shocked. An expected death is not an emergency, and what you need to do depends on the circumstances.

What to do after the death

When the person was being cared for at home and was expected to die at home, there is no need to call an ambulance or the police. You can take some time to sit with the person. If you would prefer not to be alone, call a friend or family member. If the person dies during the night, you may choose to wait until the morning to take further action.

When you feel ready, call the person's doctor and a funeral home. The doctor will sign a medical certificate confirming the death. This is needed to make funeral arrangements. The funeral director can register the death with the Registrar of Births, Deaths and Marriages, who will provide a death certificate.

If the death occurs in a palliative care unit, hospital or residential aged care facility, there's usually no need to rush. You can have time alone with the person before the nurses explain what needs to be done. Some people want to wait until other family members or friends have had the opportunity to say goodbye.

Several organisations will need to be told of the death. The Department of Human Services has a useful checklist of who may need to be notified. Visit their website at humanservices.gov.au and search for 'What to do following a death'.

“ I had promised Mum that after she died, I would make sure she had her favourite lippy on. I did this at the funeral parlour before the final viewing of her body. She was wearing the dress we had chosen together. ” Judith

Funeral and religious services

Many people have no previous experience organising a funeral and little knowledge of what to do. Funerals can be an important part of the grieving process. They allow family and friends to share their grief, say goodbye and celebrate the person's life.

The executor of the will or a family member usually arranges the funeral. Most people use a funeral director, who can organise the service, coffin, newspaper notices and flowers, and help with many of the legal responsibilities such as registering the death. However, you do not need to use a funeral director and can organise these details yourself if you prefer.

If the person has a prepaid funeral plan, it will usually include details of what they wanted and also which funeral director to use. Sometimes a person may not have prepaid their funeral plan, but may still have left written instructions or talked to you about their wishes.

If you don't know the person's wishes, you might need to make the decisions yourself. This can be difficult and stressful, especially as other family members may have different ideas about what should happen.

You can look for a funeral director by visiting the Australian Funeral Directors Association at afda.org.au or calling them on 1300 888 188, or by visiting Funeral Directors Australia at funeraldirectorsaustralia.com.au.

Wills and probate

A will is a legal document stating how the deceased person's belongings (assets or estate) are to be distributed after their death. The executor of the will is responsible for distributing the person's assets to the people named in the will. This happens after any debts are paid. Probate is the process of having the will validated by the courts. This has to be granted before the executor can release any of the assets.

Financial matters

You may be eligible for financial assistance after an immediate family member has died. The Department of Human Services provides a number of payments and services to the spouse, partner or children. Check to see if you're eligible for a bereavement allowance or payment, double orphan pension, widow allowance or pension bonus bereavement payment at humanservices.gov.au.



Cancer Council has online fact sheets about what happens to the superannuation, income, assets or unpaid debts of someone who has died. Visit your local Cancer Council website to download them, or call **13 11 20** if you need help finding them.

Grief

Grief is a natural response to losing someone you love. It can be both a physical and emotional response. The feelings you may experience include sadness, numbness, disbelief, loneliness, and even guilt, anger, relief and acceptance. You might have trouble sleeping, cry a lot or have difficulty crying, lose your appetite, or not be interested in your usual activities.

There's no right or wrong way to grieve, and everyone mourns in their own way and their own time. It may be according to religious or spiritual practices, but it can also be more personal. Even though your relative or friend is no longer physically present, they remain part of you and your life. This ongoing connection can be a source of comfort in your grief.

You might feel pressure from yourself or others to get over it and get on with life, but grief has no set time line. It can seem like a roller-coaster – sometimes you might feel yourself 'coming good' and then swiftly go downhill again for a while. The sorrow may never go away completely, but most people gradually adapt to the loss. The pain will usually become less intense as you come to terms with how your life has changed.

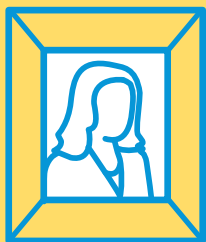
Sometimes, the pain does not seem to ease over time. If you're concerned that your grief is stopping you from living your life, professional support may be helpful (see page 75).

Call 13 11 20 for a free copy of *Understanding Grief*, or download a digital version from your local Cancer Council website.

Ways to remember

You may want to do something special to acknowledge and honour the life of your family member or friend after they've died. Some people find this helps them cope with their loss.

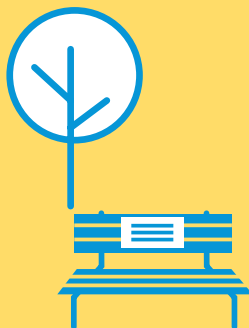
Frame a photo or a cherished note or other memento.



Cook their favourite meal on their birthday.



Plant a special tree or flower.



Light a candle.

Create a scholarship or annual award in their memory.



Place a memorial plaque in a favourite spot.



Make a contribution to their preferred charity or community group.

Create an online memorial page with photos and stories.



Further support and information

A range of services are available to help people throughout the process of dying and to support their family and friends.

Carer services

Carers Australia**1800 242 636**carersaustralia.com.au

National body working with state and territory carers associations to provide information and counselling for carers.

Carer Gateway**1800 422 737**carergateway.gov.au

Practical information and resources for carers, and links to support services in your local area.

Young Carers**1800 242 636**youngcarers.net.au

Support and information for young people who are caring for a family member who is ill.

Counselling and mentoring

beyondblue**1300 22 4636**beyondblue.org.au

24-hour telephone counselling service; online and email counselling available 7 days a week.

Kids Helpline**1800 55 1800**kidshelpline.com.au

Telephone and online counselling service and crisis support for young people aged 5–25.

Lifeline**13 11 14**lifeline.org.au

24-hour telephone crisis support and suicide prevention service.

MensLine Australia**1300 78 99 78**mensline.org.au

Telephone and online support and referral service for men with family and relationship concerns.

Cancer Council's Peer Support Programs 13 11 20	People affected by cancer who you can connect with online, by phone or in person.
Funerals	
Australian Funeral Directors Association 1300 888 188 or 03 9859 9966 afda.org.au	Listing of funeral directors and information about prepaying or planning a funeral.
Funeral Directors Australia funeraldirectorsaustralia.com.au	Listing of independent funeral directors and information about planning a funeral.
Funeral Celebrants Association Australia funeralcelebrants.org.au	Directory for finding a funeral celebrant in your local area.
Future planning	
Advance Care Planning 1300 208 582 advancecareplanning.org.au	Information about planning for your future health care, including advance directives.
Dying to Talk dyingtotalk.org.au	Palliative Care Australia website encouraging Australians to talk about dying; includes a discussion starter.
The GroundSwell Project thegroundswellproject.com	Community organisation using creativity to promote resilience and wellbeing throughout all phases of life.

Grief

Australian Centre for Grief and Bereavement

1800 642 066

www.grief.org.au

Online information for people experiencing grief.

GriefLink

grieflink.org.au

Online information for the bereaved and grieving, their carers, friends and colleagues.

GriefLine

1300 845 745

griefline.org.au

Community and family services to support all Australians who have experienced a loss.

Practical assistance

Independent Living Centres Australia

1300 885 886

ilcaustralia.org.au

Advice on a range of products and services to help with aspects of day-to-day living.

Home help and transport

Contact your local council, your palliative care team or Cancer Council **13 11 20** to find out if you can get help with housework, meals or transport.

Home nursing

Some home nursing can be organised as part of your palliative care; private services are also available – check if your private health fund covers them.

Legal and financial information

Cancer Council Legal and Financial Referral Service 13 11 20	Can connect you with a lawyer or financial adviser if you need professional advice about legal or financial issues; free assistance for eligible clients.
End of Life Law in Australia end-of-life.qut.edu.au	Information from the Australian Centre for Health Law Research to help you understand the law relating to advance directives, stopping treatment, palliative care, and euthanasia.
Centrelink 132 717 humanservices.gov.au	Offers financial support for people with a long-term illness and for primary carers.
National Debt Helpline 1800 007 007 ndh.org.au	Not-for-profit service that outlines how to tackle debt problems and explains how to find a financial counsellor for free, independent advice.
Public Trustees Australia publictrusteesaustralia.com	Gateway for all public and state trustees in Australia, who can help you prepare a will and manage your finances.
Talk to the social worker on the palliative care team.	May be able to help you access legal or financial support.

Palliative care

Palliative Care Australia

palliativecare.org.au

Provides information and resources and can link you to your local palliative care office.

CareSearch

caresearch.com.au

Australian Government website that provides palliative care information and links to services for patients and families, as well as resources for health professionals.

Spiritual care (pastoral care)

Contact your hospital.

Many hospitals have a spiritual care practitioner (pastoral carer) who can talk to you about practical and spiritual concerns (from all religious and non-religious viewpoints).

Support groups

Telephone support groups

Cancer Council **13 11 20**

Includes groups for people with advanced cancer, for carers, and for the bereaved.

Cancer Council Online Community

cancercouncil.com.au/OC

An online discussion forum where people can connect with each other at any time, ask or answer questions, or write a blog of their experiences.



Glossary

advance care planning

When an individual thinks about their future health care and discusses their wishes with their family, friends and health care team. The written record of these wishes may be called an advance care plan or advance care directive.

advanced cancer

Cancer that has spread deeply into the surrounding tissues or away from the original site (metastasised) and is less likely to be cured.

capacity

Having the ability to make decisions and understand the impact of those decisions.

carer

A person who provides physical and/or emotional support to someone who is living with a disability or a disease such as cancer.

complementary therapies

Supportive treatments that are used in conjunction with conventional or palliative treatment. They may improve general health, wellbeing and quality of life, and help people cope with cancer symptoms and treatment side effects.

delirium

A disturbed mental state that can have a range of physical causes and can involve: a lower level of consciousness; memory loss; seeing things that aren't there; mood swings; and sleep disturbances. It is sometimes experienced near the end of life.

depression

Very low mood and loss of interest in life, lasting over two weeks; can cause physical and emotional changes.

dyspnoea

The medical term for difficulty breathing. Also called breathlessness.

enduring power of attorney

A document that gives a person the ability to act on your behalf on financial and legal matters should you lose the capacity to make your own decisions.

enduring power of guardianship

A document that gives a person the ability to make personal, health and lifestyle decisions on your behalf should you lose the capacity to do so.

euthanasia

The act or practice of deliberately ending the life of a person suffering from a terminal illness or incurable condition. It is illegal in Australia (as at January 2017).

hospice

See palliative care unit.

life-limiting illness

When an illness is unlikely to be cured and will cause death at some stage. A person with a life-limiting illness may live for weeks, months or even years.

malignant

When cells are cancerous, which means they can spread (metastasise) and may eventually cause death if they cannot be treated.

metastasis

A cancer that has spread from another part of the body. Also known as secondary cancer.

morphine

A strong and effective pain reliever commonly used for people with cancer.

palliative care

The holistic care of people who have a life-limiting illness, their families and carers. It aims to maintain quality of life by addressing physical, practical, emotional and spiritual needs.

palliative care nurse

A nurse who specialises in the field of palliative care and is experienced in helping patients, families and carers with end-of-life care.

palliative care specialist

A doctor who has specialised in the field of palliative medicine, prescribes medical treatment for pain and other symptoms, and supports and advises the other members of the palliative care team, and the patient, family and carers.

palliative care unit

A place that provides comprehensive care for people with a life-limiting illness. This may include inpatient medical care, respite care, and end-of-

life care for people who are unable or prefer not to die at home.

prognosis

The likely outcome of someone's disease.

quality of life

Your comfort and satisfaction, based on how well your physical, emotional, spiritual, sexual, social and financial needs are met within the limitations of your illness.

recurrence/relapse

The return of a disease after a period of improvement.

spiritual care practitioner

A palliative care team member who can help meet your spiritual needs. May be called a pastoral carer or chaplain.

terminal restlessness

A type of delirium featuring agitation that can occur near the end of life.

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancervic.org.au/glossary
- cancersa.org.au/glossary

References

1. A Anastasios, *Dying to know: bringing death to life*, Hardie Grant Books, Melbourne, 2010.
2. SP Halpern, *The etiquette of illness: what to say when you can't find the words*, Bloomsbury, New York, 2004.



How you can help

At Cancer Council, we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls' Night In and Pink Ribbon Day, or hold your own fundraiser or become a volunteer.

Make a donation: Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

Buy Cancer Council sun protection products: Every purchase helps you prevent cancer and contribute financially to our goals.

Help us speak out for a cancer-smart community: We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



Cancer Council

13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

Cancer Council services and programs vary in each area.

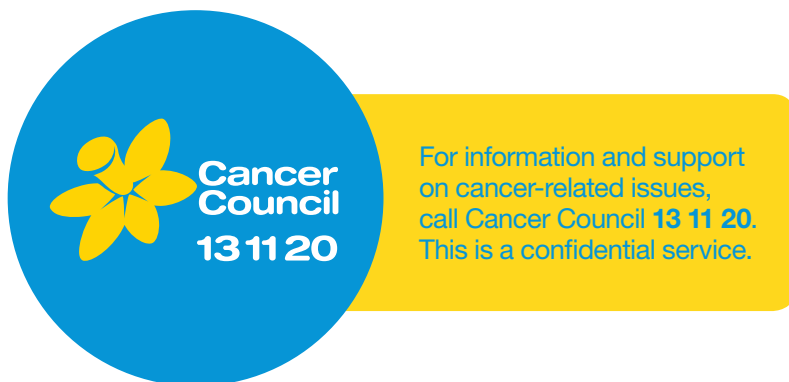
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



If you need information in a language other than English, an interpreting service is available. Call 13 14 50.



If you are deaf, or have a hearing or speech impairment, contact us through the National Relay Service.
www.relayservice.gov.au



Produced in collaboration with:



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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To support Cancer Council, call your local Cancer Council or visit your local website.*